

Operating Principles of the Public Health Data Standards Consortium

11/27/00

Name

The name of the organization shall be the Public Health Data Standards Consortium (PHDSC) and may be referred to hereinafter as the “Consortium” or the “PHDSC.”

Background

On November 2-3, 1998, the National Center for Health Statistics of the Centers for Disease Control and Prevention, in conjunction with the Agency for Healthcare Research and Quality and the National Committee on Vital and Health Statistics, convened a workshop to examine the implications of the Health Insurance Portability and Accountability Act of 1996 (HIPAA) for the practice of public health and health services research. The workshop, “The Implications of HIPAA’s Administrative Simplification Provisions for Public Health and Health Services Research,” brought together 85 leaders in health statistics, research, and informatics to examine the challenges and opportunities presented by HIPAA.

Workshop participants developed consensus recommendations for establishing a consortium to organize the public health and the health services research communities on data standards issues. This consortium serves as a mechanism for ongoing representation of public health and health services research interests in data standards setting processes including HIPAA implementation.

What is the Consortium?

The Consortium is a coalition of organizations committed to the promotion of data standards for public health and health services research through the collaboration of state, federal and private sector organizations. This involves using existing voluntary standards established by the standards development organizations (e.g., ANSI ASC X12 and HL7) and the data content committees (e.g., National Uniform Billing Committee and National Uniform Claim Committee), where applicable, and encouraging participation in the standards process where current standards do not meet public health needs.

The Consortium has adopted the definition of public health in the U.S. as developed by the Public Health Functions Steering Committee in 1994. The public health vision, as exemplified in the objectives of the Healthy People 2010 initiative, is healthy people in healthy communities and the mission is to promote physical and mental health and prevent disease, injury and disability. Public Health prevents epidemics and the spread of disease, protects against environmental hazards, prevents injuries, promotes and encourages healthy behaviors, responds to disasters and assists communities in recovery, and assures the quality and accessibility of health services. Health Services Research supports the functions of public health through data gathering, research and information exchange on the delivery, quality and financing of the health care system.

The Consortium is committed to comprehensive, integrated, and coordinated health data standards that are clinically sound as well as culturally relevant and consumer- and family-friendly. Thus, decisions about standards will consider the needs of a community-based as well as a population-based approach.

The consortium is not an advisory body to the Department of Health and Human Services or any other governmental agencies regarding data standardization issues. Advice or recommendations to the Department of Health and Human Services can be provided by the individual member organizations, or groups of member organizations, or by the Consortium to the National Committee on Vital and Health Statistics, which is the advisory committee to the Department on health information policy.

Mission

The mission of the PHDSC is to improve the health and health care of the U.S population through improved health related information by expanding involvement in existing health data standards and content organizations. The Consortium will determine standards needs through consultation with stakeholders, facilitate the use of existing national standards and identify priorities for the development of new national data standards for public health and health services research. The Consortium will work with its members and other partners to educate the public health and the health services research communities about health data standards issues.

Goals and Strategies

- Improve the health and health care of the U.S. population through improved health related information
- Convene local, state, and national health services researchers and public health practitioners around data standards issues, utilizing existing organizations to facilitate communication with and disseminate information to other stakeholders
- Identify high priority data needs that can be met through the HIPAA transaction and clinical standards, as well as other standards setting processes (e.g., ANSI X12 and HL7)
- Encourage participation and seek formal representation on data content committees (e.g., National Uniform Billing Committee and National Uniform Claim Committee)
- Educate public health practitioners, health services researchers and other stakeholders about standards issues, working through member organizations as appropriate
- Promote Consortium efforts, and relevant efforts of other data organizations and committees, to help ensure continued access to health care information by public health practitioners and by health services researchers, with the appropriate safeguards for confidentiality of individually identifiable data

Membership

Consortium membership is open to any organization with a public health focus and with an interest in data standardization for the purposes of health services research and public health practice. These members may include any organization that collects, generates, or uses public health data to improve the physical and mental health of a population.

Member Organizations currently include: (as of 11/27/00)

Agency for Healthcare Research and Quality (AHRQ)
Association for Health Services Research (AHSR)
Association of Public Health Laboratories (APHL)
Association of State and Territorial Health Officials (ASTHO)
California Cancer Registry
California Office of Statewide Health Planning and Development (OSHPD)
CDC's National Center for Health Statistics (CDC/NCHS)
Centers for Disease Control and Prevention (CDC)
Coalition for Health Services Research (CHSR)
Center for Mental Health Services (CMHS)/Substance Abuse and Mental Health Services Administration (SAMSHA)
Council of State and Territorial Epidemiologists (CSTE)
Health Care Financing Administration (HCFA)
Joint Commission on Accreditation of Healthcare Organizations (JCAHO)
Massachusetts Health Data Consortium (MHDC)
Mental Health Statistics Improvement Program (MHSIP)
Minnesota Health Data Institute (MHDI)
National Association of County and City Health Officials (NACCHO)
National Association of Health Data Organizations (NAHDO)
National Association of Public Health Statistics and Information Systems (NAPHSIS)
National Association of State Alcohol and Drug Abuse Directors (NASADAD)
Nebraska Health and Human Services System
New York Statewide Planning and Research Cooperative System (SPARCS)
Public Health Foundation (PHF)
State and Territorial Injury Prevention Director's Association (STIPDA)
Wisconsin Bureau of Health Information
Workgroup for the Computerization of Behavioral Health and Human Services Records (WGCBHHSR)

Additional Organizations invited to join the Consortium are:

American Hospital Association (AHA)
American Medical Association (AMA)
Association of Maternal and Child Health Programs (AMCHP)
Health Resources and Services Administration (HRSA)
National Association of Local Boards Of Health (NALBOH)
National Academy for State Health Policy (NASHP)
National Association of State Medicaid Directors (NASMD)
National Committee for Quality Assurance (NCQA)
Utah Health Information Network (UHIN)

Member Organizations' Roles and Responsibilities

- Designate Consortium Steering Committee Principal and Alternate member
- Participate in all Consortium meetings and conference calls

- Disseminate information regarding Consortium activities to its members and/or public health practitioner clients, and all public and private sector stakeholders (including consumers, families, and consumer advocates) affected by Consortium recommendations
- Solicit feedback from its members on any Consortium business and necessary issues
- Promote the activities of the Consortium at any of its meetings as feasible
- Subscribe to the Consortium listserv and participate in listserv discussions regarding issues of data standardization for health services research and public health
- Participate in discussions and decision-making regarding Consortium workplan and projects and be involved in consortium activities as able and as necessary
- Represent Consortium proposals at the appropriate data standards development organization or data content committee
- Identify and obtain support from other members of their organization to work on Consortium projects, work groups, etc.

Steering Committee

The Steering Committee will include one principal representative and an alternate from each organization, who will facilitate the above roles and responsibilities for their respective organization. Principal and alternate representatives will serve for a maximum of two years, with possibility of membership renewal by their respective organization. If an alternate representative assumes the role as principal representative during the two-year period, the two-year tenure will initiate on the date that the principal representative role is assumed.

Planning Group

The Planning Group for the Consortium will consist of up to ten individuals selected annually by the Steering Committee and will include the federal and state representatives of the Consortium to both the National Uniform Billing Committee and the National Uniform Claim Committee. This Group will perform the administrative functions of the Consortium such as: scheduling and planning meetings, seeking out and ensuring budgetary resources, keeping consortium records including all meeting minutes, and maintaining the Consortium website and listserv.

Standing Work Groups

The Consortium Steering Committee may establish Standing Work Groups to be responsible for projects that the Steering Committee determines would address on-going and dynamic issues in data standardization. Any member of a Consortium member organization with an interest in, and some knowledge of, the subject matter can serve as either member or chair of a Standing Work Group. Standing Work Groups will be permanent entities of the Consortium until otherwise determined by the Steering Committee, and will report directly to the Steering Committee. Members of a Standing Work Group will serve for a period of one year with possibility of renewal. Assessment of membership will be made at the Consortium's Annual Steering Committee meeting.

Ad Hoc Work Groups

Ad hoc workgroups may be created to assume responsibility for coordination and implementation of any project approved by the Consortium Steering Committee. Any member of a Consortium member organization can serve as either member or chair of an ad hoc work group. An ad hoc workgroup will cease to exist when its work has been completed and it has submitted a final report to the Consortium Steering Committee.

Discussion and Decision Making

All members will work together to define problems and generate options to reach decisions by consensus. All members will work toward a common understanding and agreement that considers all interests. This involves discussions to explore all interests and needs in an effort to reach a mutually acceptable agreement.

The purpose of this consensus process is to:

- Establish an open and creative atmosphere;
- Ensure effective participation;
- Honor the perspective of all participants;
- Encourage and recognize the different perspectives in a group;
- Resolve disputes;
- Maintain Consortium focus, balance and purpose; and
- Get positive results.

Consensus is established when, in the judgment of the Steering Committee, substantial agreement has been reached. Substantial agreement means more than a simple majority, but not necessarily unanimity. All views and objections will be considered and an effort made toward their resolution. If a consensus is not reached, the Steering Committee, using all available information, will make the final decision.

Voting

Voting can occur at any meeting of the Steering Committee or at any broader Consortium meeting. Each member organization is allowed one vote, either by that organization's principal representative or alternate. Voting may also occur by electronic mail sent by the representative or alternate.

Funding

To the extent possible, member organizations will bear the cost of participation in the Consortium.

Meetings

The Consortium shall meet at such time and place as is determined by the Steering Committee. The form of such meetings may be face-to-face or by teleconference as deemed appropriate. Consortium meetings may also be scheduled as an adjunct to the annual meeting of one of its member organizations. Meeting times will be no less than annually. Members will receive advanced notice.

Quorum

A quorum for purpose of conducting the business of the Consortium shall consist of representatives of the majority of the Steering Committee member organizations.

Minutes

The Planning Group will ensure that minutes of each meeting are prepared and published on the Consortium website.

Communication

As a medium for information dissemination and for the discussion of data standards issues, the Consortium has established a listserv called the PH-CONSORTIUM-L. Subscription to this listserv is not restricted to member organizations but is open to anyone who wishes to participate. To subscribe, the individual must submit a request to listserv@list.nih.gov with the following in the body of the letter: subscribe ph-consortium-l *your name*. Access to the listserv is also available on the Internet at <http://list.nih.gov>.

The Consortium website is www.cdc.gov/nchs/otheract/phdsc/phdsc.htm.